



## Complete Summary

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### GUIDELINE TITLE

Massachusetts Department of Mental Retardation health screening recommendations.

### BIBLIOGRAPHIC SOURCE(S)

Massachusetts Department of Developmental Services. Massachusetts Department of Mental Retardation health screening recommendations. Boston (MA): Massachusetts Department of Developmental Services; 2007. 2 p.

### GUIDELINE STATUS

This is the current release of the guideline.

This guideline updates a previous version: Massachusetts Department of Mental Retardation, Univ of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research. Preventive health recommendations for adults with mental retardation. Boston (MA): Massachusetts Department of Mental Retardation and University of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research; 2003 Sep 19. 2 p.

## COMPLETE SUMMARY CONTENT

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## SCOPE

### DISEASE/CONDITION(S)

- Intellectual disability, learning disability, mental retardation, including Down syndrome
- Cancer (breast, cervical, colorectal, testicular, prostate, and skin)
- Infectious diseases (sexually transmitted diseases, human immunodeficiency virus [HIV], hepatitis A, B, and C, tuberculosis, influenza, pneumonia,

- tetanus, diphtheria, pertussis, measles, mumps, rubella, human papillomavirus infection, varicella, shingles)
- Hypertension
- Hypercholesterolemia
- Diabetes
- Dysphagia and aspiration
- Cardiovascular disease
- Osteoporosis
- Hearing and vision impairments
- Glaucoma
- Depression
- Dementia

## **GUIDELINE CATEGORY**

Prevention  
Screening

## **CLINICAL SPECIALTY**

Family Practice  
Internal Medicine  
Preventive Medicine

## **INTENDED USERS**

Health Care Providers  
Patients  
Physician Assistants  
Physicians

## **GUIDELINE OBJECTIVE(S)**

To present preventive health recommendations for adults with intellectual or developmental disability (mental retardation)

## **TARGET POPULATION**

Adults ( $\geq 19$  years of age) with intellectual or developmental disability (mental retardation)

## **INTERVENTIONS AND PRACTICES CONSIDERED**

### **Screening**

#### *Cancer Screening*

1. Breast mammography with clinical breast exam as appropriate
2. Pelvic examination and pap smear
3. Fecal occult blood testing (FOBT)
4. Sigmoidoscopy

5. Colonoscopy
6. Clinical testicular examination
7. Digital rectal exam (DRE)
8. Prostate specific antigen (PSA)
9. Skin examination

#### *Other Screening*

1. Body mass index (BMI)
2. Blood pressure
3. Blood lipid levels
4. Blood glucose levels
5. Liver function tests
6. Dysphagia and aspiration screening
7. Cardiovascular disease screening
8. Bone mineral density (BMD)

#### *Infectious Disease Screening*

1. Chlamydia and gonorrhea screening
2. Human immunodeficiency virus (HIV) screening
3. Hepatitis B and C screening
4. Tuberculin skin testing

#### *Sensory Screening*

1. Hearing exam
2. Vision exam
3. Eye exam for glaucoma

#### *Mental and Behavioral Health Screening*

1. Depression assessment
2. Dementia assessment

#### *Screening for Persons with Down Syndrome*

1. Thyroid function test
2. Cervical spine x-ray
3. Echocardiogram

### **Prevention**

1. Health maintenance visit
2. Oral health visit
3. Immunizations for:
  - Influenza
  - Pneumococcal pneumonia
  - Hepatitis B and A
  - Tetanus, diphtheria, pertussis (Tdap)
  - Measles, mumps, and rubella (MMR)

- Human papillomavirus (HPV) infection
  - Varicella
  - Zoster virus infection (shingles)
4. General counseling and guidance

## **MAJOR OUTCOMES CONSIDERED**

Not stated

## **METHODOLOGY**

### **METHODS USED TO COLLECT/SELECT EVIDENCE**

Searches of Electronic Databases

### **DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE**

Comprehensive review of available Medline/PubMed sources, comparison to general population screening measures (Massachusetts Quality Health Partnerships), materials developed by advocacy and state agencies

### **NUMBER OF SOURCE DOCUMENTS**

Not stated

### **METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE**

Expert Consensus (Committee)

### **RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE**

Not applicable

### **METHODS USED TO ANALYZE THE EVIDENCE**

Review

### **DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE**

Literature review using structured evaluation of strength of evidence. Consensus review with expert clinical panel (see "Description of Methods Used to Formulate the Recommendations" field)

### **METHODS USED TO FORMULATE THE RECOMMENDATIONS**

Expert Consensus

## **DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS**

The development of the recommendations required careful consideration of many elements in the lives of adults with mental retardation.

### **Phase I**

Committee members received a package of reference material for review prior to the initial meeting. Members reviewed the general findings from the literature search and discussed their own professional experience in community care for people with mental retardation. Following discussion, committee members agreed to adopt generally accepted *Massachusetts Health Quality Partners (MHQP)* guidelines for the general population as a baseline and develop recommendations for modifications to address areas of greater concern for the population of people with mental retardation.

Based on findings in the literature and the experience of committee members, three focus areas emerged:

1. The need to review and modify generic MHQP standards to ensure they are appropriate to the health needs of the adult population with intellectual disability.
2. The need to facilitate effective communication relating to an individual's health, lifestyle, adaptive functioning, and service plan between residential staff or family members and the community clinician.
3. The need to consider additional recommendations for sub-populations such as those with identifiable syndromes or comorbid conditions that are associated with additional health risks.

The committee formed three sub-groups and each group was charged with developing recommendations to address one of the above areas.

### **Phase II**

Subcommittees met to develop recommendations that were shared at a second Advisory Committee meeting. The entire Advisory Committee reviewed and commented on the work of each subcommittee. The subcommittees then formed their final recommendations.

### **Phase III**

The final meeting and discussion of the Advisory Committee was held for discussion of the remaining work of each committee. Subcommittee members agreed to complete recommendations for the final report to be forwarded to the Department of Mental of Retardation (name changed to Department of Developmental Services as of July 1, 2009).

These recommendations were revised in October 2005 and July 2007.

## **RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS**

Not applicable

## COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

## METHOD OF GUIDELINE VALIDATION

Peer Review

## DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not stated

## RECOMMENDATIONS

### MAJOR RECOMMENDATIONS

**Note:** Items that are indicated in ***Bold Italic*** are specific recommendations that differ from the Massachusetts Health Quality Partnership (MHQP) recommendations in order to reflect particular health concerns of the population with intellectual disabilities.

Procedure	19-29 Years	30-39 Years	40-49 Years	50-64 Years	65 Years +
Health Maintenance Visit	<b><i>Annually for all ages.</i></b> Includes initial/interval history, age-appropriate physical exam; height and weight measurements; preventive screenings and counseling; assessment and administration of needed immunizations.				
Oral Health Visit	Promote dental health through regular oral hygiene practices, assessment by a dentist at least every 6 months, and timely management of dental disease.				
Labs and Screenings					
Cancer Screening					
Breast Cancer: Mammography	Clinical breast exam as appropriate. Mammography not routine except for patients at high risk. Accurate and detailed history and family history will identify risk factors.	Clinical breast exam as appropriate. Annual mammography at discretion of clinician/patient.	Clinical breast exam as appropriate. Annual mammography.	Mammography annually through age 69. Age 70+ at discretion of clinician/patient.	

Procedure	19-29 Years	30-39 Years	40-49 Years	50-64 Years	65 Years +
Cervical Cancer (Pelvic Exam & Pap Smear)	First pap smear by age 21. Every 1-3 years, at clinician/patient's discretion.				May be omitted after age 65 if previous screenings were consistently normal.
Colorectal Cancer	Not routine except for patients at high risk.			Starting at age 50, fecal occult blood testing (FOBT) and sigmoidoscopy every 5 years <b>OR</b> annual FOBT <b>OR</b> colonoscopy every 10 years. Screening after age 80 at clinician/patient discretion.	
Testicular and Prostate Cancer	Prostate cancer screening not routine. Clinical testicular exam at clinician's discretion.	Digital rectal exam (DRE) for patients with risk factors for prostate cancer: family history & African-American ancestry. Prostate specific antigen (PSA) screening in high-risk patients at clinician/patient discretion.		DRE. Discuss risks and benefits of PSA blood test with patients starting at age 50. Offer PSA at clinician/patient's discretion.	
Skin Cancer	Periodic total skin examinations every 3 years between the ages of 20 and 39 and annually at age 40 and older, regardless of skin tone and color. Frequency at clinician discretion based on risk factors.				
Other Recommended Screening					
Body Mass Index (BMI)	Screen for overweight and eating disorders. Consult the Centers for Disease Control and Prevention's (CDC's) growth and BMI charts ( <a href="http://www.cdc.gov/nccdphp/dnpa/bmi/index.htm">www.cdc.gov/nccdphp/dnpa/bmi/index.htm</a> ). Ask about body image and diet patterns. <b>Counsel on benefits of physical activity and a healthy diet to maintain desirable weight for height. Offer more focused evaluation and intensive counseling for adults for BMI &gt;30 kg/m<sup>2</sup> to promote sustained weight loss.</b>				

Procedure	19-29 Years	30-39 Years	40-49 Years	50-64 Years	65 Years +
Hypertension	At every acute/non-acute medical encounter and <b><i>at least annually</i></b> .				
Cholesterol	Every five years or at clinician's discretion.				At clinician's discretion.
Diabetes (Type 2)	<b><i>At least every 5 years until age 45</i></b> . Every 3 years after age 45. Fasting plasma glucose screen for individuals at high risk. Risk factors include: family history of premature coronary heart disease (CHD), hypertension, overweight, diabetes mellitus, peripheral atherosclerosis or carotid artery disease, current cigarette smoking, or high-density lipoprotein (HDL) $\leq 35$ mg/dL.				
<b><i>Liver Function</i></b>	<b><i>Annually for hepatitis B carriers. At clinician's discretion after consideration of risk factors including long term prescription medication.</i></b>				
<b><i>Dysphagia &amp; Aspiration</i></b>	<b><i>Chronic dysphagia and gastroesophageal reflux disease (GERD) are common in individuals with developmental disabilities (DD) and neuromuscular dysfunction. Screen initially and inquire about changes at annual physical.</i></b>				
<b><i>Cardiovascular Disease</i></b>	<b><i>Screen for cardiovascular diseases and malformations earlier and more regularly than the general population. Specific syndromes and neuroleptic medications may increase risk for cardiac disease.</i></b>				
Osteoporosis	Bone density screening (BMD) <b>starting at age 19</b> when risk factors are present: long term polypharmacy, mobility impairments, hypothyroid, post-menopausal women. Periodicity of screening at clinician's discretion. Annually counsel about preventive measures including dietary calcium and vitamin D intake, weight-bearing exercise, and smoking cessation.				Provide BMD testing. Counsel elderly patients about specific measures to prevent falls.
<b>Infectious Disease Screening</b>					
Sexually Transmitted Infections	For chlamydia and gonorrhea: Sexually active patients under age 25: Screen annually. Patients age 25 and over: Screen annually, if at risk. Screen pregnant women at the first prenatal visit and in the third trimester, for all sexually transmitted infections (STIs) if at risk.				
Human Immunodeficiency Virus (HIV)	Periodic testing if at risk and testing of pregnant women at increased risk.				
<b><i>Hepatitis B and C</i></b>	Periodic testing if risk factors present.				



Procedure	19-29 Years	30-39 Years	40-49 Years	50-64 Years	65 Years +
Tuberculosis (TB)	Tuberculin skin testing ever 1-2 years when risk factors present. Risk factors include residents or employees of congregate setting, close contact with persons known or suspected to have TB.				
Sensory Screening					
Hearing Assessment	<b>Screen annually.</b> Re-evaluate if hearing problem is reported or a change in behavior is noted.				
Vision Assessment	<b>Screen annually.</b> Re-evaluate if vision problems are reported or change in behavior is noted.				
Eye Exam for Glaucoma	Every 3-5 years in high risk patients. At least once in patients with no risk factors.	Every 2-4 years	Every 2-4 years	Every 2-4 years	Every 1-2 years
Mental and Behavioral Health					
Depression	<b>Screen annually for sleep, appetite disturbance, weight loss, general agitation.</b>				
Dementia	Monitor for problems performing daily activities.	<b>In persons with Down Syndrome, annual screen after age 40.</b>			
Immunizations					
Influenza	<b>Annually</b>	<b>Annually</b>	<b>Annually</b>	Annually	Annually
Pneumococcal	<b>Once</b> , especially if at elevated risk. Once after 65 years of age, even if vaccinated before 65 years of age.				
Hepatitis B	<b>Once.</b> Reevaluate antibody status every 5 years.				
Hepatitis A	If at high risk and not previously immunized.				
Tetanus, Diphtheria, Pertussis (Tdap)	3 doses if not previously immunized. Booster every 10 years.				
Measles, Mumps, and Rubella (MMR)	If born after 1956 and have not been immunized or have laboratory evidence of immunity. Receive a second dose of measles-containing vaccine if at risk. Ages 50+: Not routine.				

Procedure	19-29 Years	30-39 Years	40-49 Years	50-64 Years	65 Years +
Human Papillomavirus (HPV) Vaccine**	Three injections given over a 6-month period to females up to 26 years old.				
Varicella (Chicken Pox)	2 doses recommended for those who do not have documentation of age-appropriate immunization or a reliable history of chicken pox (varicella).				
Zoster (shingles) Vaccine**				<b>Once</b> after age 60, not for those with weak immune systems.	
<b>For Persons with Down Syndrome</b> (in addition to the above recommendations)					
Thyroid Function Test	Every 3 years (sensitive thyroid stimulating hormone [TSH]).				
Cervical Spine X-ray to Rule Out Atlanto-axial Instability	Obtain baseline as adult. Recommend repeat if symptomatic, or 30 years from baseline.				
Echocardiogram	Obtain baseline if no records of cardiac function are available.				
<b>General Counseling and Guidance</b>					
Prevention Counseling	Annually counsel regarding prevention of accidents related to falls, fire/burns, choking and screen for at-risk sexual behavior.				
Abuse or Neglect	Annually monitor for behavioral signs of abuse and neglect.				
Preconception Counseling	As appropriate, including genetic counseling, folic acid supplementation, discussion of parenting capability.				
Menopause Management	At an appropriate age, counsel women on the changes that occur at menopause and their options for the symptom management.				
Healthy Lifestyle	Annually counsel regarding diet/nutrition, incorporating regular physical activity into daily routines, substance abuse.				

\*\*Vaccines are recommended, but may not be covered by MassHealth or Medicare in all cases.

### Preparation for an Examination

Many adults can be helped to feel more comfortable at a medical visit if they feel adequately prepared for the event. Family or support staff can be encouraged to

introduce unfamiliar items such as a stethoscope or a blood pressure cuff at home to allow the instrument to become more familiar and facilitate cooperation during an exam.

During the exam, it is helpful to prepare patients for procedures by explaining them well or allowing patients with sensory impairments to explore the instruments that are about to be used. Performing simple examinations in an office or quiet waiting room may reduce a person's anxiety.

If someone is particularly anxious or an invasive screening procedure is necessary, the clinician might consider sedation prior to the appointment. In some cases, multiple procedures can be performed while the patient is sedated (dental work, or routine blood work, for example) to reduce the number of times a person is exposed to the risks of sedation.

### **Communication**

First direct your questions to the patient to determine their own perception of their health status and needs. If communication is a problem, clinicians may have to rely on a family member or support staff to provide information relating to signs or symptoms of health concerns. Questions regarding changes in the individual's behavior and adaptive function can bring underlying physical and mental health issues to light.

### **CLINICAL ALGORITHM(S)**

None provided

## **EVIDENCE SUPPORTING THE RECOMMENDATIONS**

### **TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS**

The recommendations are based on the [Massachusetts Health Quality Partnership \(MHQP\)](#) Adult Preventive Care Recommendations 2005 and Consensus Guidelines for primary health care of adults with developmental disabilities, Canadian Family Physician, Volume 52 2006.

## **BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS**

### **POTENTIAL BENEFITS**

Appropriate preventive healthcare for adults with intellectual disability (mental retardation)

### **POTENTIAL HARMS**

Not stated

## QUALIFYING STATEMENTS

### QUALIFYING STATEMENTS

With the presentation of these recommendations, the Advisory Committee does not intend to imply that adults with intellectual and developmental disabilities all have similar health needs or that clinicians should not continue to use their clinical judgment and seek additional consultation when necessary. The Advisory Committee sees these recommendations as one of a number of steps towards ensuring that every adult with intellectual and developmental disabilities receives the most appropriate health care as an individual.

## IMPLEMENTATION OF THE GUIDELINE

### DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

### IMPLEMENTATION TOOLS

Patient Resources  
Quick Reference Guides/Physician Guides

For information about [availability](#), see the "Availability of Companion Documents" and "Patient Resources" fields below.

## INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

### IOM CARE NEED

Living with Illness  
Staying Healthy

### IOM DOMAIN

Effectiveness  
Patient-centeredness

## IDENTIFYING INFORMATION AND AVAILABILITY

### BIBLIOGRAPHIC SOURCE(S)

Massachusetts Department of Developmental Services. Massachusetts Department of Mental Retardation health screening recommendations. Boston (MA): Massachusetts Department of Developmental Services; 2007. 2 p.

### ADAPTATION

The recommendations are based on the [Massachusetts Health Quality Partners \(MHQP\)](#) Adult Preventive Care Recommendations 2005 and Consensus Guidelines for primary health care of adults with developmental disabilities, Canadian Family Physician, Vol.52 2006.

**DATE RELEASED**

2003 Sep 19 (revised 2007)

**GUIDELINE DEVELOPER(S)**

Massachusetts Department of Developmental Services - State/Local Government Agency [U.S.]  
University of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research - Academic Institution

**SOURCE(S) OF FUNDING**

Massachusetts Department of Developmental Services

**GUIDELINE COMMITTEE**

Massachusetts Department of Mental Retardation Preventive Health Standards Advisory Committee

**COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE**

*Committee members:* Victor Acquista, MD; Norberto Alvarez, MD; Bob Baldor, MD; Allen Crocker, MD; Marc Emmerich, MD; Warren Ferguson, MD; Jim Gleason, PT; Adria Hodas, RN NP; Elizabeth King, RN NP; Leo McKenna, PharmD.; Barbara Pilarcik, RN; Julie Lufkin Purtz, RN NP; Van R. Silka, MD; Carol Walsh RNC, MPH; Susan Weiner, OT

**FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST**

Not stated

**GUIDELINE STATUS**

This is the current release of the guideline.

This guideline updates a previous version: Massachusetts Department of Mental Retardation, Univ of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research. Preventive health recommendations for adults with mental retardation. Boston (MA): Massachusetts Department of Mental Retardation and University of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research; 2003 Sep 19. 2 p.

**GUIDELINE AVAILABILITY**

Print copies: Available from the University of Massachusetts Medical School, Center for Developmental Disabilities Evaluation and Research, 200 Trapelo Road, Waltham, MA 02452; Phone: (781) 642-0283; Fax: (781) 642-0162.

## **AVAILABILITY OF COMPANION DOCUMENTS**

The following is available:

- Preventive health recommendations for adults with mental retardation. Guidelines for community practitioners. Boston (MA): Massachusetts Department of Mental Retardation and University of Massachusetts Medical School Center for Development Disabilities Evaluation and Research; 2007 Sep. 2 p.

Print copies: Available from the University of Massachusetts Medical School, Center for Developmental Disabilities Evaluation and Research, 200 Trapelo Road, Waltham, MA 02452; Phone: (781) 642-0283; Fax: (781) 642-0162.

## **PATIENT RESOURCES**

The following is available:

- Massachusetts Department of Mental Retardation annual health screening recommendations. Boston (MA): Massachusetts Department of Mental Retardation and University of Massachusetts Medical School Center for Development Disabilities Evaluation and Research; 2007 Sep 26. 1 p.

Print copies: Available from the University of Massachusetts Medical School, Center for Developmental Disabilities Evaluation and Research, 200 Trapelo Road, Waltham, MA 02452; Phone: (781) 642-0283; Fax: (781) 642-0162.

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## **NGC STATUS**

This summary was prepared by ECRI on January 29, 2004. The information was verified by the guideline developer on February 26, 2004. This summary was updated by ECRI Institute on April 21, 2009. The updated information was verified by the guideline developer on May 12, 2009.

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